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Clinical Pathways for Children with Autism Spectrum Disorder
Introduction

In recognition of the growing demand for services for Kentucky children with autism spectrum disorder, the State Interagency Council for Children with an Emotional Disability (SIAC) has developed the attached document "Clinical Pathways for Children with Autism".

The SIAC is a multi-agency collaborative body created by Kentucky statute to determine and establish policy for children with severe emotional disabilities. Representatives of key state agencies that work with children, including the Division of Mental Health, the Department of Education, the Department for Medicaid Services, the Department of Juvenile Justice, the Administrative Office of the Courts and the Department for Community Based Services, as well as parents of children with severe emotional disabilities, serve on the Council. A child with autism may not be considered severely emotionally disturbed, but autism services are often provided through the same programs that serve children with severe emotional disabilities.

The work on the Clinical Pathways document began with a review of current recognized "best practices" by physicians, psychologists and other health professionals who are state university faculty and who have specialized in autism spectrum disorder. Development of the document then became the responsibility of an inter-agency workgroup, who along with the Kentucky Autism Training Center, local providers of mental health services and parents of children with autism, researched, wrote and revised this document.

The SIAC was presented the draft document which members reviewed and suggested revisions. The completed document was approved by the Council, reflecting the collaborative sanction of this effort. It is hoped that this use of this pathway will flow out through the respective agencies to local offices, community partners and parents of children with autism.

The pathway outlines a "best practices" process for assessment, evaluation, service planning, service delivery and follow-up that uses an integrated, multi-disciplinary methodology. This approach is intended to make appropriate use of resources that have been made available through recent innovations such as the Kentucky Autism Training Center and the evolution of special education and community-based mental health services. It is anticipated that this document will serve as the basis for strengthening families and building integrated, multi-disciplinary services for each member of this vulnerable population of Kentucky children.

Clinical Pathway for Autism Spectrum Disorders

Introduction

This clinical pathway is designed for a child who presents with a diagnosis of an autism spectrum disorder and may be applicable to a child with another pervasive developmental disability.

General

These themes characterize the pathway-

- The uniqueness of the disorder. Each child and his/her family will assess differently, and interventions should be suited to the family and educational circumstances.
- The necessity for training and experience in autism. Persons and organizations that diagnose or intervene should demonstrate training and experience with the disorder. Providers with training and experience in autism should meet the appropriate standards for their fields.
- The importance of evidence-based intervention. New interventions for autism are frequently publicized but should not be used until research demonstrates their efficacy. Interventions should be research-based, well-established and peer-recognized. Professionals and parents of children with autism should evaluate the appropriate fit between new interventions and their child's needs.

Assessment

When a physician refers a child for a definitive diagnosis of autism, a multi-disciplinary assessment is indicated. The child and family should be referred to a program offering a multi disciplinary assessment. Currently, in Kentucky, examples of such programs include:

- the Weisskopf Center for the Evaluation of Children, University of Louisville,
- the Bingham Child Guidance Clinic, Norton-Kosair Hospital, Louisville, and
- the Infant/Toddler Evaluation Center, University of Kentucky, Lexington.

The administration of a battery of assessments, including a functional behavioral assessment, is "best practices" and will provide valuable information to plan what specific intervention(s) will best serve the child. Examples of additional assessments are:

- the Choosing Outcomes and Accommodations for Children (COACH) measure,
- ABBLS; and
- a sensory profile.

Assessors should have training and experience in autism. These disciplines may be involved in the assessment.

- Licensed Speech Language Pathologist,
- Licensed Occupational Therapist,
- Licensed Psychologist,
- Board-certified Child and Adolescent Psychiatrist or Board-Certified Developmental/ Behavioral Pediatrician,
- Representative of early intervention program (First Steps) if child is younger than three years old; and
- Representative of Local Education Agency (if child is age three or over)

If the child is not linked to First Steps or the Local Education Authority, the family should be connected to the program at the time the assessment is planned. *(Information on how to access First Steps or special education services of the Local Education Authority may be found in the Appendix.)*

Post-Assessment Conference

When the multi-disciplinary assessment is complete, the assessors should meet with the parent(s) or other primary caregiver and the child's educator to discuss the assessment results and suggest recommendations for the child's educational placement.

If indicated, a Targeted Case Manager/Service Coordinator with training and experience in autism should also attend the post-assessment conference. The role of the Targeted Case Manager/Service Coordinator is to:

- gather information regarding the child's and family's needs,
- link the child and family to services,
- minimize barriers to accessing appropriate educational or health services; and
- mobilize supports for the family due to stress of the child's disability.

(Information on how to access targeted Case Management/ Service Coordination services may be found in the Appendix.)

The post-assessment conference should identify an instrument to measure the child's functioning at the beginning of the intervention and recommend intervals for continuing measurement as intervention proceeds.

If continuing mental health case management is needed, a Targeted Case Manager/Service Coordinator should convene a service team meeting to address behavioral concerns.

Children diagnosed with autism spectrum disorder will have an Admissions and Release Committee (ARC) through their Local Education Authority to determine educational programming and and/or other related services.

Service Planning and Intervention

If continuing mental health case management is needed, a service team meeting is convened. The service team is comprised of, at a minimum, the following individuals:

- a Targeted Case Manager/Service Coordinator with training and experience in autism,
- the child's parent(s) or other primary caregiver; and
- it is strongly recommended that a representative of the child's educational program *who works directly with the child* attend the service planning meeting.

The service plan should consider the coordination of the following domains-

- Therapies
  - ✓ Speech
  - ✓ Occupational
  - ✓ Behavioral
  - ✓ Physical
- Education
  - ✓ Consultation on development of Individual Education Plan (IEP)
  - ✓ Coordination with IEP goals and objectives
- Family
  - ✓ Education on autism spectrum disorder
  - ✓ Intervention training
  - ✓ Support needs
- Case Management
  - ✓ Coordination of school and home training

Interventions should have these characteristics-

- Focus on building family strengths. The child's primary caregivers must be involved in order to assure success of interventions across settings (home and school). Evidence based programs of in-home training and intervention for the child by the primary caregiver should be supported to the extent of the primary caregiver's resources as determined by the battery of assessments.

- Training of surrogate caregivers (such as relatives) is a secondary option and may be provided to provide consistent behavioral intervention in the absence of the child's primary caregiver.

- An in-home behavioral interventionist may provide direct services to the child. However, research indicates that for a successful outcome, this training should only supplement

training of the child by the primary caregivers in order to sustain and generalize the child's gains in functioning.

Review

In addition to service plan reviews, the multi-disciplinary team that assessed the child should re-convene annually with his primary caregiver, educator and Targeted Case Manager/Service Coordinator and should address:

- progress on objectives identified in the assessment; and
- the appropriateness of the interventions being utilized.

The annual review may be held in conjunction with a service planning meeting or the child's annual Admissions and Release Committee (ARC) meeting. Efforts should be made to coordinate the child's IEP with the plan developed by the service team.